



AUTHERAPIES

"Upgrading competences for choosing evidence-based therapies for people with autism, their relatives and their key professionals"



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European Economic
and Social Committee

Advancing Inclusive and Evidence-Based Therapies for Autism in Europe

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Preparation of a scientific publication

Information Needs of Families with Autistic Children

- Families often begin searching for information upon noticing developmental differences, even before a formal Autism Spectrum Disorder (ASD) diagnosis (Weissheimer et al., 2020a).
- A diagnosis frequently leads to insecurity due to a lack of knowledge about ASD, treatments, behaviour management, prognosis, and legal rights (Weissheimer et al., 2020a ; Weissheimer et al., 2020b).
- Comprehensive and understandable information empowers parents, enhancing their security and competence in decision-making (Weissheimer et al., 2020a).
- While professionals are key information sources, some families report them lacking necessary skills or time for adequate counselling (Weissheimer et al., 2020a).
- Inadequate or poorly delivered information can negatively impact families (Weissheimer et al., 2020a).
- Families also turn to informal networks, the internet, books, and workshops for information (Weissheimer et al., 2020b).
- In Spain, parental risk literacy, especially numeracy, is linked to family quality of life, suggesting better understanding of complex health information aids decision-making (Garrido et al., 2021).
- Information must be accessible and comprehensible to parents with varying health literacy levels.
- The Autherapies project survey indicated that 69% of autistic individuals and their families feel they lack sufficient information on EBIs, with figures being 73% in Spain, 50% in Italy, and 40% in Poland (Image 2).
- Over 70% of all groups surveyed by Autherapies (families, specialists, students) reported a lack of sufficient EBI information.



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Preparation of a scientific publication

Specialist Expertise & Knowledge Gaps in ASD Interventions

- Literature reveals concerns about specialists' knowledge and training in Evidence-Based Interventions (EBIs) for ASD.
- Systematic reviews suggest Primary Care Physicians (PCPs) may have inadequate knowledge of ASD and its treatments (Stoddart et al., 2019).
- In Spain, significant deficiencies exist in special education teachers' training on social-communication EBPs; over 70% reported these were never taught or only mentioned incidentally in initial and in-service training (Alcedo-Merino et al., 2022).
- A survey in Poland found over a quarter of specialist primary school teachers received no autism instruction during initial education, and almost half had no continuing professional development on the topic (Lisak Šegota et al., 2022).
- Italian professionals report reduced access to specialist training in the public sector and low cultural acceptance of some EBIs, like behavioural methods, often deemed "too rigid" (Cascio, 2015).
- The Autherapies survey found 68% of specialists believe their peer group lacks high-level expertise in autism therapies).
- This perception was particularly high in Spain (88%) and Poland (70%), but lower in Italy (38%).
- Clinicians face challenges due to the multitude of measurement instruments with varying relevance and limited psychometric evidence, especially regarding responsiveness to change (Freire et al., 2024 ; McConachie et al., 2015).
- The Autherapies project aims to develop training courses to address these expertise gaps (Autherapies, n.d. ; EPR, n.d.).



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Parental Decision-Making in Choosing ASD Interventions

- Parents typically assume the primary role in deciding on interventions for their autistic children (Broady et al., 2010 ; Cetiner, 2024).
- This responsibility is often challenging, with parents feeling overwhelmed by information and lacking clear guidance on appropriate treatments due to ASD's heterogeneity (Broady et al., 2010).
- Parental perceptions, beliefs, and existing knowledge significantly shape their intervention priorities and choices (Cetiner, 2024).
- The concept of "choice" can be a burden, sometimes imposed as a responsibility, and can drive medicalisation (Broady et al., 2010).
- Parents often act as advocates with little formal knowledge, leading to stress and disempowerment (Broady et al., 2010).
- The Autherapies survey revealed over 70% of families, specialists, and students find it difficult for families to choose among different autism interventions (Image 3).
- Approximately 50% in each group surveyed by Autherapies believe families do not make informed decisions regarding interventions (Image 3).
- Furthermore, 44% of specialists/students and 35% of families believe loved ones do not choose the best EBIs (Image 3).
- Coordinating disconnected services with little institutional support adds to parental stress (Broady et al., 2010 ; Davico et al., 2023).



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Preparation of a scientific publication

Access to Information and Evidence-Based Interventions

- Difficulties in accessing reliable and understandable information about EBIs are consistently reported (Weissheimer et al,2020).
- The Autherapies survey found over 60% of specialists and over 75% of families believe it is difficult to access the information needed to choose appropriate interventions (Image 3).
- Effective translation of research evidence into meaningful and usable formats for families is crucial (Broady et al., 2010).
- Systemic issues in service provision impact access; for example, Poland faces long waiting times, regional inequalities, and insufficient support for adults with ASD (Chojnicka et al., 2023).
- Poland also lacks a specific national autism strategy, unlike Spain (Kawa and Ropar, 2018). Spain has a national strategy, but dissemination of EBPs into teacher training appears limited (Alcedo-Merino et al., 2022).
- Integrated care pathways are needed to improve service coordination across an individual's life (Davico et al., 2023).
- Intersectionality, including race/ethnicity and social disadvantage, can create additional barriers to accessing information and services (Brighton & Hove City Council, 2024).
- The Autherapies project highlights that an estimated 70% of people with autism may receive treatments based on alternative medicines without scientific evidence, underscoring access issues to EBIs (Autherapies, n.d.).
- Diagnoses are still difficult or too late to obtain in many countries (Autism Europe, 2019).



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Results of the Questionnaire

- At the beginning of the Autherapies project, a survey was conducted in the partner countries, covering:

94 individuals on the autism spectrum, their family members, and organizations representing people with autism and their families.

335 specialists from the healthcare and education sectors working with autistic individuals, in Spain, Italy, and Poland.



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Results of the Questionnaire

69% of surveyed persons with autism and their families believe that this group does not have sufficient information about evidence-based interventions for autism (73% in Spain, 50% in Italy, and 40% in Poland).

This highlights the need to take action to provide people with autism and their families with sufficient information about evidence-based interventions for autism.

Furthermore, 68% of respondents working with individuals on the autism spectrum believe that this group does not possess a high level of expertise in autism therapies (88% in Spain, 38% in Italy, and 70% in Poland).

This knowledge gap among specialists regarding autism therapies is concerning, as it may hinder access for people with autism and their families to information about evidence-based therapies.



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Conclusions of the Questionnaire

Over 70% of families, specialists, and students believe it is difficult for families to choose among different autism interventions.

44% of specialists and students, and 35% of families, believe that their loved ones do not choose the best evidence-based interventions for autism.

Over 70% in each group believe there is a lack of sufficient information about evidence-based interventions (EBI) for families and individuals with autism.

Approximately 50% in each group believe that families do not make informed decisions regarding interventions. Over 60% of specialists and over 75% of families believe it is difficult to access the information needed to choose appropriate interventions.



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Results of the Questionnaire

The heterogeneity of results across countries indicates that there may be different systems in Europe for informing people with autism and their families about evidence-based interventions, as well as different ways of training healthcare and education professionals in autism treatment, with varying success rates.

In 2023, the European Parliament adopted a resolution on harmonizing the rights of autistic people across the EU.

The EU Strategy for the Rights of Persons with Disabilities (2021-2030), aimed at implementing the UN Convention on the Rights of Persons with Disabilities, includes only limited actions concerning the situation of people with autism.

Although the strategy introduced initiatives regarding accessibility, exercising EU rights, independent living, equal access and non-discrimination – including to healthcare, as well as safety and protection – it did not contain any specific initiatives concerning autism or the accessibility of evidence-based therapies.



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Strategic Integration of Autism EBI Education

1. Mandate EBI Content in University Curricula

- Recommendation: Ministries of Health and Education should mandate core autism and EBI modules across medical, nursing, psychology, pedagogy, and therapy programs.
- Justification: AUTHERAPIES findings show 70% of professionals and students lack sufficient EBI knowledge.
- Implementation: Introduce a national standard requiring EBI modules in professional licensing curricula.

2. Use AUTHERAPIES Modules as Core Resources

- Recommendation: Adopt Modules 1–4 of AUTHERAPIES as official teaching material.
- Justification: Scientifically grounded, interdisciplinary, user-friendly; includes validated therapies and discredits pseudotherapies.
- Action: Integrate into CME programs and teacher training via ORE.



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3. Develop EBI Certification Tracks

- Recommendation: Create optional/mandatory certification in EBIs with AUTHERAPIES and academic partners (e.g., ŚUM, Fundacja JiM).
- Outcome: Graduation credential indicating clinical and pedagogical readiness.
- Model: Based on AUTHERAPIES framework.

4. Train for Shared Decision-Making and Advocacy

- Recommendation: Include training on legal rights, AAC, and advocacy (AUTHERAPIES Module 4).
- Goal: Enable professionals to treat autistic individuals as partners in care, including those with high support needs.



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5. Critical Appraisal of Evidence

- Recommendation: Teach students to analyze therapy evidence using AUTHERAPIES (GRADE, SIGN, RCTs, etc.).
- Purpose: Combat pseudoscience and misinformation in professional settings.
- Outcome: Increased clinical integrity and accountability.

6. Promote Multidisciplinary Learning

- Recommendation: Run joint simulation courses across disciplines.
- Format: IPET development, mock consultations, therapy selection simulations.
- Goal: Reflect the reality of interdisciplinary autism care.



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5. Institutionalize AUTHERAPIES Nationally

- Recommendation: Ministries to distribute AUTHERAPIES content via CME, teacher training centers (ORE), and inspectorates.
- Tool: Build a national autism therapy repository based on AUTHERAPIES.

8. Embed in Referral Pathways

- Recommendation: Require PPPs and Early Support Points (Wczesne Wspomaganie Rozwoju) to provide AUTHERAPIES-based materials at ASD diagnosis.
- Goal: Standardize post-diagnosis guidance, reduce regional disparities.



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9. Introduce EBI Education Audits

- Recommendation: Audit EBI integration in faculties via MEiN or NFZ, with AUTHERAPIES partners.
- Metrics: Competency levels, tool usage, pseudotherapy exposure reduction.

10. Promote Student-Led Awareness Projects

- Recommendation: Encourage dissemination campaigns by students, especially in rural areas.
- Result: Improve public awareness and promote evidence-based care uptake.



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